Animate

Towards Transformation Leadership Framework - capturing the learning 2021 -2024

1. Introduction and purpose

This paper aims to capture the story and key learning points of the development of the Towards Transformation Leadership Framework to date. It is intended as a resource for people seeking to work in a collaborative, person-centred way with autistic people and people with learning disabilities, putting them at the centre of addressing the challenges they face accessing services and support.

2. Background and context

In March 2021, the Scottish Government published the Towards Transformation Plan 'to shape supports, services and attitudes to ensure that the human rights of autistic people and people with learning/intellectual disabilities are respected and protected and that they are empowered to live their lives, the same as everyone else.'[1] The plan was conceived in partnership with Convention of Scottish Local Authorities (COSLA) and a range of stakeholders, and included a particular focus on addressing the challenges autistic people and people with learning disabilities experienced during the Covid-19 pandemic. The Plan[2] said:

"We will put in place plans for everyone to work together through new leadership arrangements and for this work to be led by autistic people and people with a learning/intellectual disability. National and local organisations need to be involved in this.

"We want the voice of autistic people, people with a learning/intellectual disability, and unpaid carers to be at the centre of work going forward.

"We will also be led by autistic people and people with a learning/intellectual disability about how much of this they want to do together."

Autistic people told the Scottish Government and COSLA that their mental health had been severely affected by the pandemic including being denied mental health services as a direct result of being autistic. They said that autistic people often feel they are not understood by professionals and are more likely to have had a negative experience in mental health services.

Recognising this severity of this experience, the Scottish Government and COSLA committed to addressing these issues through a new leadership and engagement process. The Scottish Government enlisted Inspiring Scotland's Autism Advisory Forum (a group of over 150 autistic adults from across Scotland who advised on the Increasing Understanding of Autism programme and Different Minds campaign) and The Assembly (an accessible politics forum that aims to make politics accessible to people with learning disabilities and autistic people)

[1] https://www.gov.scot/publications/learning-intellectual-disability-autism-towards-transformation/pages/3/
[2] Towards Transformation Plan, Scottish Government 2021

to understand the challenges that autistic people and people with learning disabilities face when trying to access mental health services.

3. Concept design - ambitions of the Driver/Mechanic/Engineer concept

The Scottish Government, with support from Inspiring Scotland, The Assembly, and others worked with people with lived experience to establish a new leadership and engagement process that put the voices and experiences of autistic people and people with learning disabilities firmly at its heart.

The leadership and engagement process included creating and establishing ways of working based on the belief that 'the most effective and most sustainable change is made by the people who need and use services, in partnership with the decision makers at all levels.' The desire was to effect 'systems change' by working together to achieve a vision of a Scotland that best supports autistic people and people with learning disabilities.

Key stakeholders were invited to take up a range of related roles and to work together collaboratively to identify, plan and implement action to improve the way mental health services are provided to, and experienced by, autistic people and people with learning disabilities.

The roles created included ***Drivers***, ***Allies*** *and* ***Engineers***, as described below.

- ***Drivers*** are people with lived experience of autism or learning disability, at the centre of the work.
- ***Allies*** are people who have an interest in or experience of championing the human rights of autistic people or people with a learning disability and who are committed to working together with those people with lived experience to highlight the issues affecting them and support them to make real, lasting change in their lives.
- ***Engineers*** are people with connections to or who are local and national decision makers. They will hear the results of the engagement and consultation work, suggested solutions from the people with lived experience and support them in partnership with Allies to make the solutions a reality. The Engineer group will be a group for action, they will work together to help create and implement the essential parts of the solutions informed by lived experience knowledge and evidence and research.

The concept of the Mechanic role did not materialise in practice as the work progressed.

The three groups were supported by the Scottish Government Autism and Learning Disabilities policy team, Inspiring Scotland, The Assembly and others to work together to:

- Identify and recommend priority areas for action and proposed solutions
- Submit the recommended solutions to the Scottish Government and COSLA for consideration, and
- Plan and deliver actions with others in respect of agreed priorities.

A range of fundamental underpinning principles were agreed, namely:

- A Human Rights Approach is adopted in line with the United Nations Convention on the Rights of Persons with Disabilities
- The work is evidence-based
- The work will be led by people with lived experience
- The language used has been agreed with people with lived experience and is used consistently
- This is a collaborative approach
- Feedback to everyone involved is provided regularly.

Governance

The following governance arrangements were established to explain role relatedness, clarify expectations and lines of accountability:

- Decision making rests with Ministers, COSLA and with Local Authorities, informed by interactions between Drivers, Allies and Engineers.
- The Engineers are responsible for making recommendations to Ministers and COSLA, in line with the agreed priorities based on discussion with the Drivers and research.
- The Drivers have an advisory role and will be supported to lead and develop the vision.
- The Scottish Government Autism and Learning Disabilities policy team have responsibility for implementation of key policies for autistic people and people with a learning disability, including the Towards Transformation Plan and the management of the leadership and engagement work. This includes programme management of the work. They will be fully informed by the recommendations of the Engineers using the advice from the Drivers.

4. Methodology /way of working – the evolution of the accessible working model

The way of working developed over a number of phases, ***Understand, Define, Prioritise, Design,*** and ***Test*** as described below.

4. 1 Understand (March - December 2021)

This included:

- Conception of the approach through Towards Transformation policy conversations
- Recruiting the Drivers, Engineers and then Allies in 2022
- Research on accessing mental health services with autistic people, people with learning disabilities, parents and carers.

The leadership work was planned and developed by Scottish Government, Inspiring Scotland and others. The leadership structures proposed a collaborative and innovative approach based on authenticity and lived experience at the centre. The process sought to empower autistic people and people with learning/intellectual disabilities to be the leaders in transforming Scotland and to engage those with the ability to make the changes needed by those with lived experience.

Autistic Peoples Organisations (APOs) and Learning Disability Organisations (LDOs) were encouraged to contribute their views to the concept development and research stages.

Recruiting the Drivers
The Driver role was advertised through The Assembly and the Autism Advisory Forum.

Key to the process was ensuring that everyone involved was enabled to fully participate in the discussions, and that communication support and any adjustments required for individuals were put in place. Facilitators familiar with best practice were engaged to help shape conversations and meetings and make them as inclusive as possible.

Recruiting Engineers
Engineers were chosen for their potential to influence and progress the agreed actions and reflect a wide range of sectors and services to match the vast cross cutting nature of the topic area of mental health.

Recruiting the Allies (February 2022)
The Allies were invited to take part by the Learning Disabilities and Autism team in Scottish Government based on existing and long-standing engagement and working relationships. Each of the Allies had demonstrated a commitment to both the Keys to Life strategy, Autism Toolbox and Towards Transformation Plan implementation and their work evidenced an alignment with the vision and outcomes of the Leadership Framework.

4.2 Define (September 21 – September 2022)
This included:

- Research - reports and presentations
- Literature review and recommendations

Consulting autistic adults and parents and carers
In September 2021, a survey topic guide was developed in conjunction with 10 members of the Autism Advisory Forum, Autistic People-led Organisations (APOs), National autistic charities and Scottish Government.

In November 2021, Assenti Research were commissioned to undertake two pieces of primary research into autistic adults, and parents and carers of autistic adults and adults with learning disabilities experience of accessing mental health services, respectively[3]. The methods used comprised: quantitative online surveys, qualitative focus groups and individual depth interviews with autistic adults.

The survey was adapted by The Assembly Programme Manager who completed one to ones with a range of Assembly members with a learning disability and/or autism. Focus groups, facilitated by five different autistic people, were held with the Autism Advisory Forum, and five focus groups similarly held with parents and carers of adults with learning disabilities, through the Assembly.

[3]https://inspiringscotland.org.uk/wp-content/uploads/2023/10/Autistic-Community-Report-2021-1.pdf and https://inspiringscotland.org.uk/wp-content/uploads/2023/10/Autistic-Community-Report-2021-Easy-Read.pdf

While there were some responses that were particular to autistic adults (see 4.3 below), there were many fundamental commonalities in the findings of the two pieces of research. Both cohorts highlighted that:

- Undiagnosed mental health issues were common
- They had a poor experience of seeking and receiving mental health support and encountered multiple and complex barriers
- They were left with feelings of frustration, mistrust, and cynicism as a result of negative experiences.

Their recommendations for improvement included:
For primary care (including social care and community-based support)

- Autism and learning disability informed training to improve understanding about the relationship with mental health for all frontline staff, especially GPs
- An easier appointment booking system (e.g. online booking) and longer appointment times
- Improve awareness of mental health services (including third sector).

For secondary care mental health services

- Autism and learning disability informed training, to adapt their approaches for the wide range of people they may treat
- Communication about the expected waiting time, self-care suggestions, and how to get help quicker if things get worse
- Provide clear information in advance of appointments e.g. waiting time expectations, length of appointment, who they will see, what will be asked/discussed, what happens next
- Establish sensory and communication needs (ideally in advance) and adapt the environment and approach to suit
- Offer alternative approaches to suit their needs, e.g. one-to-one's, Autistic groups (as appropriate), digital, creative therapy etc.
- Enable flexible appointments to meet their needs – allow time for questions to be processed and answers considered.

General recommendations:

- Enable people to communicate in their preferred way, e.g. offering digital appointments, allowing people to bring written notes, communicating in writing during the appointment and offer alternative approaches for those who are non-verbal or have limited communication
- Keep questions specific and offer examples of the type of answer they might give
- Make allowances for difficulties with executive functioning, e.g. missing appointments – offer reminders.

A Rights Based Approach

In December 2021, Fiona Clarke, autistic advocate and consultant, was commissioned to produce a briefing paper[4] for the Drivers and Engineers on a Rights Based Approach to services for autistic people and people with learning disabilities.

The paper highlighted that autistic people and people with learning disabilities have the same right as everyone else to participate in decisions that affect them, both directly and through representative organisations, enshrined in law. However, they face significant attitudinal, physical, legal, economic, social and communication barriers to their participation. The paper identified the PANEL Principles (Participation, Accountability, Non-discrimination and equality, Empowerment, Legal) as a helpful lens through which to promote a human rights approach, and the Scottish Human Rights Council's Human Rights Based Approach – A Self-Assessment Tool as a useful resource for embedding it. It also included a list of detailed resources to support participation.

Literature review

In January 2022, The National Autistic Implementation Team (NAIT) was commissioned to undertake a Rapid Review of Mental Health in Autistic Adults, focusing on 'Prevalence, Interventions and Outcomes'[5].

The review focused on peer-reviewed literature and data published between January 2011 and 2021. It aimed to explore:

- The prevalence of Mental Health amongst Autistic Adults
- The effectiveness of various Mental Health Interventions and Supports
- The outcomes of these interventions.

NAIT's review found that further research is needed on the specific needs of autistic adults and that autistic people require informed support that adapts to their needs over time.

Autistic Drivers were keen that the research also highlighted primary studies, theoretical papers and other non-peer-reviewed literature (including articles and websites), so together with NAIT they produced an addendum listing a range of such resources in March 2022.

The Scottish Learning Disabilities Observatory were commissioned to produce a review of evidence of 'Mental ill health and behaviours that challenge in adults with learning/intellectual disabilities'. The review looked at high quality studies of adults aged 18 and over published in peer reviewed journals that included: data relevant to the prevalence of mental ill health or behaviours that challenge, access to evidence-based interventions and services and/or outcomes of mental ill health or behaviours that challenge.

It concluded that there are still significant gaps in the availability of high-quality evidence relating to the prevalence, accessibility of services and clinical effectiveness of treatment of mental ill health and behaviours that challenge in the population with learning/intellectual disabilities. It recommended that:

[4] https://inspiringscotland.org.uk/wp-content/uploads/2024/06/Rights-Based-Approach-Fiona-Clarke.pdf

[5] https://www.thirdspace.scot/wp-content/uploads/2021/12/Research-Summary-Mental-Health-in-Autistic-Adults-2021-with-Appendices.pdf

- New learning disabilities research is needed that addresses the mental health and behavioural needs of people with learning/intellectual disabilities
- Mental health and behaviours that challenge assessments be included in annual health check programme
- All health and care staff should receive learning/intellectual disabilities awareness training, information should be provided in accessible formats and care should be delivered locally, and
- Robust services should enable adults with learning/intellectual disabilities and behaviours that challenge to be supported in their local communities.

4.3 Prioritise (2022)

This stage included:

- Drivers, Allies and Engineers discussing priorities based on the research findings
- Scottish Government assesses short, medium and longer terms actions to address and presents to Drivers.

Engineers meeting (April 2022)

In February 2022, invitations were sent to Engineers and Allies by the Scottish Government policy team, to attend the first Engineers meeting in April. A series of seven preparatory meetings, for the event were held to share the vision of the process, spend time looking at the research, to make sure people had the opportunity to ask questions, and to talk through the different roles of the people involved. They comprised:

1. Autism Drivers preparation session
2. Autism Drivers human rights approach workshop
3. Allies preparation session
4. Learning disability Drivers preparation session
5. Research deep dive autism
6. Research deep dive learning disability
7. Engineers preparation session

The sessions were augmented by additional one to one meetings for Drivers who a further opportunity to discuss their role and contribution.

The Engineers meeting was held on Zoom and attended by 79 participants, the majority of whom were autistic and learning disability Drivers (17/79), followed by 17 Engineers including the Minister for Mental Wellbeing and Social Care. There were a relatively high number of supporters, facilitators and scribes (18 of 79) which were required given the format of the online meeting.

The meeting had two breakout sessions to enable smaller group discussions, with each breakout group including Drivers who had spoken about the breakout room theme in previous meetings, plus a facilitator and scribe.

The meeting focused on four priority areas from the research, respectively:

Learning disability	**Autism**

1. Access to face-to-face community mental health support 2. Accessible information about accessing mental health support and services 3. Training for GPs and health care professionals 4. Education about mental wellbeing and ill mental health	1. Mental health services – delays and navigating the system 2. Training, understanding and experience among health professionals 3. Post diagnostic support and ongoing lifelong support 4. Autism informed services and flexibility

The meeting looked at how these issues could be addressed in the short term (the next year) and in the longer term (over a year).

Accessibility

The report noted accessibility challenges experienced by participants. Significant consideration had been given to trying to replicate best practice in supporting the accessibility needs of participants when preparing for and organising the meeting. However, individuals have differing needs and in trying to create a session that worked for everyone some fundamental challenges were evident.

Although the meeting agenda was produced in Easy Read format for the learning disability Drivers, the target of issuing papers two weeks in advance to allow adequate time for preparation was not achieved.

Trying to meet differing communication needs and preferences also proved challenging. Autistic participants expressed a preference for using the Zoom chat function to contribute rather than speaking during the meeting or breakout rooms. While this was welcomed, it created challenges for the learning disability Drivers for whom processing information appearing in the chat can be difficult. It was agreed that further discussion with the Drivers on how to create accessibility for all when bringing both groups together was needed.

Drivers also identified meeting new people and progressing to the point of working together as challenging, and it was recommended that there was significant investment in building relationships.

Themes were identified for each of the priorities and next steps proposed and committed to as follows:

1. Outlining what can be done to make improvements in mental health support and services in the short term
2. Considering the strengthening of relationships and what participants can do to make this happen and agreeing collective action
3. Production of a report on the meeting.

For the Engineers phase, the following process expectations were expressed:

- All participants come up with a working agreement
- Problems and solutions (short, medium and long term) are discussed
- Solutions are reported back to the Drivers and discussed with lived experience groups

- Solutions are passed to change makers for implementation.

Additional feedback from Drivers was collected following the meeting, as summarised below:

Autistic Drivers

Prior concerns

- Concerned that without funding the situation will remain the same
- Concern around who Engineers are. Some wanted a commitment that a certain percentage of the Engineers will be autistic professionals
- Some Drivers felt that their own professional experience needed to be made clearer to the Engineers
- Disappointment that autistic people are 'only there to tell their story which is so often the case'. 'We *are always there to be interpreted' but we are not able to interpret the data'*
- APOs and Drivers highlighted gaps in NAIT's Literature review: that 'good autistic led research was not included' e.g. AMASE's *Too complicated to treat* had not been acknowledged. APOs generally felt that they have expertise that is not being used.
- Some Drivers and APOs were concerned with the pace and expressed doubts about whether anything positive will happen through this process.

Process feedback

- Expressed a need for clarity on funding, time commitment over next six months and impact on other work commitments, tax and benefits
- Frustration with technical issues on Zoom, facilitators lack of research understanding and not bringing the chat into the meeting – request that comments be read out to ensure both verbal and written discussions were noted
- Clear sense that bringing autistic and learning disability Drivers together in one large virtual meeting did not work for either group – they have vastly different communication needs which cannot be met by bringing them together
- How to measure outcomes and evaluate to ensure the work is on the right path
- Concerns no Engineer representatives from GPs, counsellor organisations, Justice, Call Scotland, CAMHS.

Summary of common themes across the learning disability and autism groups[6]

A further report summarised the common areas of discussion and where solutions that would benefit both autistic people and people with learning disabilities emerged across the eight breakout groups in the Engineers meeting.

Knowledge and understanding *(cited by seven of eight groups)*

- Ensuring GPs and health practitioners have a good understanding of learning disability (including profound and multiple learning disability) and autism so they can provide appropriate and effective mental health care.
- Ensuring there is support and resources across practitioners' careers about how best to support autistic people and people with learning disabilities.

[6] https://inspiringscotland.org.uk/wp-content/uploads/2024/06/Common-themes-report-2022.pdf

Accessibility of services *(cited by five of eight groups)*

- Ensuring that access to GP appointments and the appointments themselves are best suited to the needs of autistic people and people with learning disabilities.
- Ensuring the time of the day and year mental health services are available reflects the needs of people.

Capacity of services to provide support - including diagnosis *(cited by three of eight groups)*

- Pressure on GP time
- The number of specialist services available (including for autism diagnosis)
- Knowing what the waiting time is for mental health and autism diagnosis services

Counselling and support services *(cited by three of eight groups)*

- There is a need for more NHS counsellors (especially those trained in learning disability and Autism)

Early intervention *(cited by two of eight groups)*

Making sure there is content about mental health and wellbeing covered in early years and school education for autistic people and pupils with learning disabilities.

In July 2022, in line with the governance guidance, these options were reviewed by Scottish Government and COSLA to consider the potential short, medium and long term solutions and where responsibility lay.

Leadership Framework: accessing mental health services Drivers and Allies meeting (September 2022)

The purpose of the meeting was to agree the priority areas to be focussed on, drawing on the suggestions that resulted from the Engineers meeting in April and the follow up of Drivers and Allies in August. It was further informed by the two Scottish Government suggestions papers that categorised the short, medium and longer term options following the July governance meeting.

The Scottish Government team advised that some of the 'long list' of suggestions from the Engineers meeting needed further clarification before they could be categorised and recommended that others needed to be withdrawn because they were either beyond the remit of the policy team, or not feasible and could not be funded.

The Drivers were asked to focus on the short-term suggestions, select the ones they wanted to begin with so that working groups of Drivers, Allies and the Scottish Government team could work out between them how to take the actions forward.

This was the first in-person meeting of the Drivers, Allies and the Scottish Government team, and followed preparatory online meetings of the Drivers and Allies in August to enable them to meet and discuss roles and responsibilities.

The meeting was held in the Scottish Government offices at St Andrew's House, Edinburgh and a lot of thought and effort was put into trying to ensure participants were prepared for

the meeting including being able to overcome additional security measures required to access and move around the building. These included:

- Information about when, where, and how to get to the meeting including visuals of St Andrew's House, what the meeting rooms looked like, and the lunch menu.
- Information on expenses
- The agenda for the meeting, and preparatory reference papers in advance
- The type of questions that would be asked to enable people to think about the topic in advance. Autism Drivers were offered the opportunity to make any comments or suggestions on this paper, by adding comments to a Google document
- An information pack which addressed some of the questions and concerns raised by the Drivers around the Engineers meeting.

The meeting was attended by 41 people, comprising: 10 autism Drivers, six learning disability Drivers, four Driver supporters, eight Scottish Government policy staff, eight Allies, and five Inspiring Scotland staff. It was organised in two rooms due to the capacity of the rooms available and the desire to respond to the information preferences expressed by both groups of Drivers. It was intended that the two groups of Drivers work separately to each identify three points to be shared with the other group.

The learning disability Drivers identified the following to share with the autistic Drivers

1. GP accessibility issues was a key theme
2. We need to look at what training is available already for healthcare professionals
3. We suggest looking at a pilot GP practice to test this with.

They emphasised that lived experience must be at the heart of the work.

The autistic Drivers used the time available for a more general discussion and requests for additional information were made in order to help them to decide on their key points at a future time. Their requests included a more detailed explanation of how the pre-existing research informed the priorities and proposed solution, and what Drivers could do to help bring the priority forward and understand what's needed from them. The policy team recommended they all refer back to the governance guidance in the Leadership Framework in relation to role descriptions, role relatedness and decision-making responsibilities, to ensure consistency in implementing them. Similarly, it was recognised that the next phase of the work required the generation of resources and that the specific asks of both the autistic and learning disability Drivers was still to be determined and agreed.

Next steps

The policy team agreed to follow up with the autistic Drivers, and to:

- Draw up actions, outcomes and timelines for each priority area and share these with the Drivers and Allies
- Identify and contact the most appropriate Engineers to help support actions and working groups.

Feedback on accessibility arrangements

Although much detailed work had gone into preparing people for the meeting, as outlined above, the meeting still had its challenges. These included the autistic Drivers group

overrunning by 60 minutes and some people finding the security requirements for entry to and moving around St Andrew's House intrusive.

Process evaluation (July to October 2022)[7]

Animate Consulting were commissioned by Inspiring Scotland to undertake a process evaluation of the Leadership Framework. This involved a series of one-to-one conversations with a sample of 18 participants across the diversity of the leadership and engagement process (autistic Drivers, Allies, Engineers and the Scottish Government team), and a focus group with six learning disability Drivers and support workers.

The evaluation recognised the ambition of the venture and the complex challenges working in this relational way, trying to meet the diverse information and communication needs of individuals and the differing hopes and expectations of the range of participating individual's and organisation's demands.

It found that the Allies, Drivers and Engineers were appreciative of the commitment to genuine co-productive working, exemplified in the team's willingness to listen, learn and adapt the process in response to feedback. It highlighted the paramount and continuing need to keep clarifying the purpose of the process, the roles of the participants, and shared expectations on scope and timescale to ensure the success of the initiative. This included the ensuring participants were clear about the limitations of the process, and the constraints of the power and gift of the Scottish Government team in the context of the competing demands of the internal Scottish Government decision-making system.

It highlighted a range of ongoing tensions around speed, depth and convenience built into the co-production approach, including:

- The need to move quickly on issues which affect the day-to-day lives and human rights of people with learning disabilities and autistic people and the importance of slowing down enough that everyone can get on board and understand the information which is presented to them
- The need to provide everyone with enough information without swamping them with too much
- The need to involve everyone with a stake in the process, from the outset but also at a time when they can make a genuine and meaningful contribution
- The need to make meetings accessible by working online whilst acknowledging the benefit of in person workshops to develop relationships and improve communication.

It recognised that the next stage of the process would involve the working groups coalescing around the prioritised options, and that this would provide a natural opportunity to reset.

A range of recommendations were made and agreed by the Scottish Government team, including:

[7] https://inspiringscotland.org.uk//wp-content/uploads/2023/11/Animate-Leadership-Process-Evaluation-Final-Report.pdf

- Hearing from a wider range of voices from across the autistic and learning disability communities including younger people (18- 25 years), BME people, and those with more severe communication needs
- Ensuring all participants receive the same information in accessible formats in sufficient time to prepare for meetings, and travel support to attend
- Increasing the frequency of meetings and pre-meeting preparatory and linking sessions with the autistic Drivers to aid flow and continuity
- More opportunities to meet together as Engineers, Allies and Drivers in separate groups as well as collectively to develop trust, working relationships and a shared understanding of the process, scope and limitations.
- Developing a working agreement that is based on the PANEL principles, capturing what each party needs to collaborate and work well together
- Exploring the possibility of engaging an autistic facilitator to co-facilitating meetings
- The Scottish Government and COSLA continuing to engage and bring in public sector Allies and Engineers with decision making powers and leverage to enable and accelerate change.

Animate also undertook a rapid review of 'Good practice in participatory approaches to working with autistic people and people with learning disabilities[8]'. It concluded that the participatory approach being pursed and further developed by the Scottish Government team was in line with good practice in Scotland and elsewhere.

A systematic review[9] - which pooled a sample of 28,154 study participants predominantly from studies in North America, the UK and Europe - examined the effectiveness, facilitators, and barriers of interventions for social, community and civic participation for adults on the autism spectrum, or with intellectual or psychosocial disability. It concluded that 'improved social and community participation requires purposeful strategies that identify meaningful participation preferences (e.g., where, when, how, and with whom) and provide support to build capacity or enable ongoing participation. Community capacity building, peer support and advocacy may also be needed to make the community more accessible, and to enable people to exercise genuine choice.'

The commitment to the meaningful ongoing participation of autistic people and people with learning disabilities in the development of current and future workplans, places lived experience at the centre of policymaking and the co-creation of informed implementation on a more equitable basis.

4.4 Design (2023)

This included:

- Creating working groups
- Working groups take first priority area and co-produce outputs and activity to address.

[8] Good practice in participatory approaches to working with autistic people and people with learning disabilities – Animate Consulting, January 2023

[9] Frontiers in Rehabilitation Sciences, Melita J. Giummarra, Ivana Randjelovic and Lisa O'Brien, August 2019 - https://www.frontiersin.org/articles/10.3389/fresc.2022.935473/full

The working groups were created in October 2022 to take the plans forward, with Drivers and Allies signing up to the groups they were interested in joining. In November they held their first meetings, and agreed a way of working and outline timescales, and how they would communicate progress with The Assembly, Engineers and Allies.

Three working groups were formed as described below:

Learning disability Drivers - GP and practice staff working group

- Agree, develop and test resources needed to raise awareness and improve general understanding of what it is like to live with a learning disability and more explicitly how their mental health is impacted, and the challenges and barriers faced in accessing mental health services and supports.

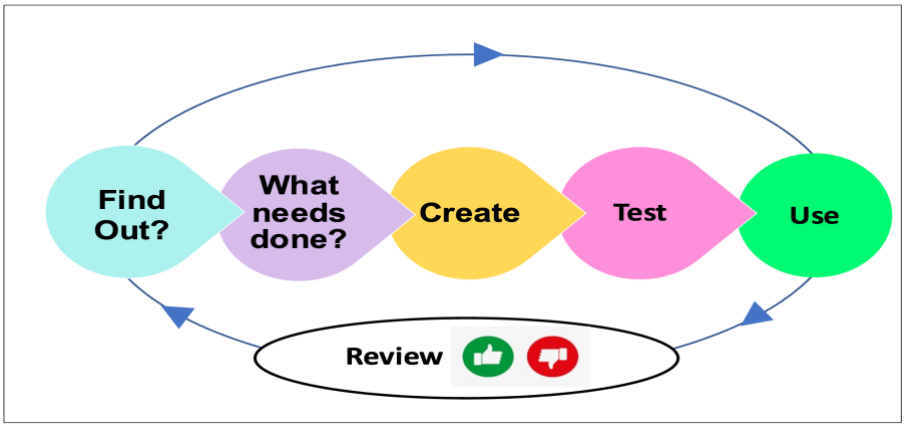
Autistic Drivers - GP and other practice staff working group

- To develop training materials and resources to make GP services more accessible to autistic people and support improved mental health.

Autistic Drivers - Autism Informed Services working group

- To develop co-produced informed level professional learning resources for all NHS professionals working in adult services or with adults. This includes mental health services.

The learning disability Drivers were engaged in developing an accessible planning and evaluation model which the autistic Drivers also agreed to use:



Building on the learning from the process evaluation, the working group teams continued to work closely with the policy and support team being readily available, listening, taking advice, giving time and consideration to Drivers concerns.

An autistic Facilitator was recruited to address the 'double empathy problem', recognising that when people with very different experiences of the world interact with one another, they struggle to empathise with each other. Drawing on both their lived experience and facilitation skills, they were able to improve communication within the working groups, and to support them to make progress. This co-facilitative approach greatly enabled the effectiveness of the work with the autistic Drivers groups.

Relevant Engineers were involved in the working groups, negating the need for further general Engineers meetings, and monthly written updates on progress were communicated to Drivers, Allies and Engineers from January 2023.

4.5 Test (2023-24)

This included:

- Creating resources to be tested
- Preparing to carry out tests

Learning disability Drivers - GP and practice staff working group

The learning disability Drivers decided to remain as one group of 10 and to concentrate on one of their key priorities.

They connected with NHS 24 and the Scottish Ambulance Service (SAS) as potential sites to test resources aimed at improving healthcare staff understanding of how the mental health of people with learning disabilities is impacted by the challenges and barriers faced in accessing mental health services and supports.

NHS 24 and SAS representatives attended Assembly meetings to talk to the Drivers and the wider membership around the current services and people with a learning disability. It was decided to delay the work with GPs until after the winter peak period.

It was agreed that the resources would be created by the Drivers and tested on a small scale with NHS 24 and SAS partners before a wider roll out. The Drivers would work in partnership with NHS 24 and SAS to increase the accessibility and awareness of their services among people with a learning disability and their families and carers.

Brief summary of GP and practice staff working group progress (December 2023)

Find out

- Group considered what GP/NHS 24 and SAS staff training is currently in place
- Discussed who to target in these settings
- Drivers shared personal experiences

What needs done?

- Group came up with top 10 tips for health professionals
- Group asked the wider Assembly membership about the top 10 tips and what they would prioritise
- People said all 10 were important
- Drivers identified how these top 10 tips could be applied by medical professionals

Create

- Scoping work with potential the test sites (and Engineers), building relationships and agreeing to work together with the sites.
- Short-term working group established with NHS 24

The group is creating a suite of resources, formed of:

- Film with top 10 tips
- Film on behind the scenes
- 3 things card
- Booklet on top 10 tips
- Poster on top 10 tips

The resources will use dynamic QR codes, which means:

- They can be easily updated
- They can be interfaced with AI
- It is accessible for people with learning disabilities
- They provide good data for evaluation – e.g. the QR code data will be able to identify where the link was opened geographically, and how many times.

Test

The aim is to test the **Learning Disability Top 10 tips** developed by the Learning Disability Drivers and colleagues, as set out below, in four GP surgeries across Inverclyde, NHS 24, Scottish Ambulance Service and possibly NHS Fife in 2024. The agreed Top 10 tips are:

1. Listen to me
2. Believe me
3. Value me
4. Give me accessible information
5. Create an environment that works for me
6. Give me the time I need
7. Speak to me first
8. Explain to me and show me what you are going to do
9. Use simple words
10. Check if I understand

The working group developed a questionnaire with baseline questions based on the experience and learning of implementing mandatory learning disability training in England (the Oliver McGowan training).

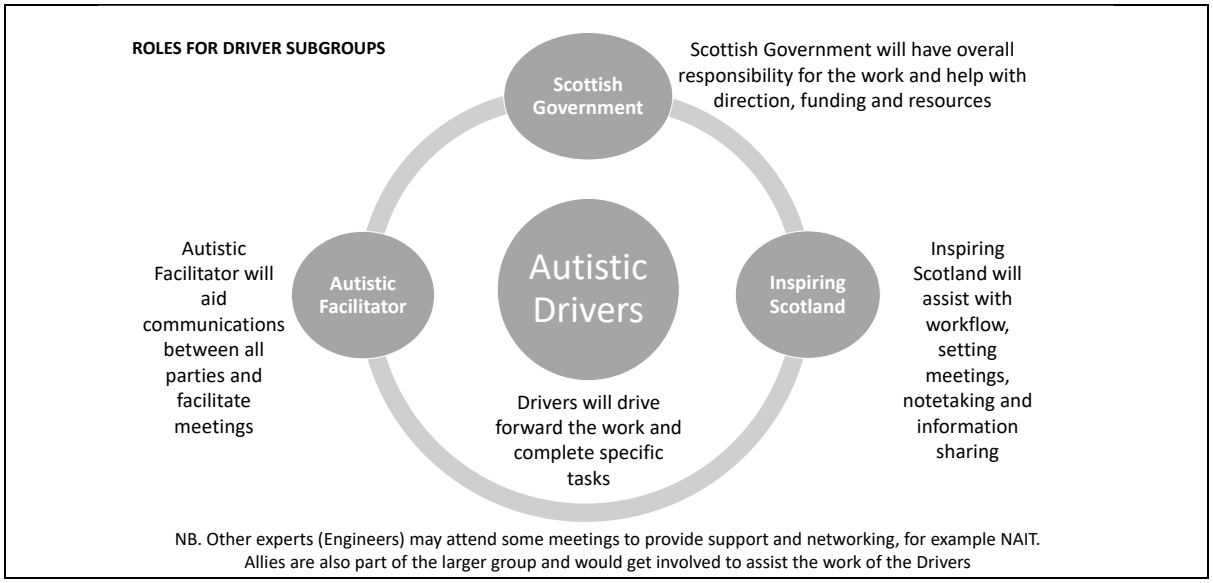
The testing will take place in 2024. There will be slightly different testing approaches in each setting e.g. NHS 24 is a telephone service so this will need to inform the test approach.

Autistic Drivers

The Drivers met with Inspiring Scotland individually to agree which group they wanted to work in. Two groups were established: Training for GP and practice staff (Group 1) with six Drivers and Autism Informed Services (Group 2), with seven Drivers.

The Drivers agreed meeting protocols which were also made available in Easy Read. An autistic facilitator was introduced to co-facilitate the meetings alongside Inspiring Scotland, and the Drivers chose a Google Jamboard as their preferred communication tool for both groups between meetings. The Drivers were additionally offered an optional group briefing and debriefing pre and post meetings.

The roles and responsibilities of the collaborating partners was set out and agreed as illustrated in the diagram below:



Group 1: Training for GPs and practice staff

As indicated above it was agreed that the pilot with GP surgeries would be put on hold until winter peak period over.

The group was supported to devise tasks and then asked to select which tasks they wished to work on. Some of the group decided to prepare a guide based on their own experience of good support from GPs, while others decide to review academic articles on good practice and research practical examples used elsewhere.

The group intended to create a range of resources aimed at different staff in a practice and other patients who may be autistic. Contact was established with an autistic GP in Shetland who was happy to look at the resources prior to testing in GP surgeries and rolling out more widely.

Brief summary of GP and other practice staff progress (December 2023)

Find out

- Took the research findings from the Assenti Research report relevant to GPs and mental health support, including:

"Autism informed training for all frontline staff but especially GPs to improve Autism understanding and the relationship with mental health. The vast majority of respondents had approached their GP for help with mental health issues, and it is essential for them to have a much better understanding."

- Drivers shared their personal experiences of seeing GPs and the things that make a difference
- Drivers shared their experience of developing and delivering autistic led training for GPs

What needs done?

- The group came up with an idea for a film. The film would cover things identified in the research that make a difference when making an appointment and seeing your GP (whilst recognising that materials already exist but more autistic perspective and experience is needed)
- The group felt a poster for GP surgeries could pull out the key messages in the film

Create

- A workshop with Drivers was held to develop the framework for the film script
- Working group meetings then developed the film script and poster content
- Members of the group shared GP contacts. Connections were made with these GPs to ask for comment on the draft film script. Comments were provided from two GPs on the draft film script
- A test outline was shared with all Allies and Engineers with a request to highlight any gaps identified or similar work to be aware of.

The group is creating resources, formed of:

- A film sharing and depicting the experiences of making an appointment and seeing a GP. This was created by Ability Academy, an autistic-led film company
- Two posters for GP surgeries with key messages highlighted from film. The poster visuals were created by an autistic illustrator.

Test

The aim is to test the difference in GP and practice staff understanding of autism and their practice with autistic patients after watching the film.

The questionnaire with baseline questions developed by the learning disability working group was adapted.

The testing will take place in 2024 in two GP practices.

Group 2: Autism Informed Services

NAIT provided articles and a general update on their overview of training. NES were suggested as a key partner who could help implement improved training resources.

Drivers completed a questionnaire designed by NAIT to assist them in agreeing on the focus of the work of the group. They agreed that:

- the aim of the work was *"To develop co-produced informed level professional learning resources for all NHS professionals working in adult services or with adults. This includes mental health services."*
- the intended audience was all staff working in health settings, including clinical and non-clinical staff, and

The outcomes they were looking for included:

- autistic people (diagnosed or not) will have positive experiences of healthcare and experience an inclusive sensory and physical environment

- health professionals will:
    - put adjustments in place to ensure that care and support is accessible to autistic people
    - take a neurodiversity affirming approach
    - provide predictability
    - recognise the difference between anxiety and depression in neurotypical people and autistic burnout
- keep their learning about neurodivergence up to date, and
- take account of the differences between neurodivergent norms and neurotypical norms.

On advice from NAIT the Drivers agreed not to map existing training as it would not serve the prime purpose.

It was agreed that the resources will be created by the Drivers and tested on a small scale before wider roll out.

Brief summary of Autism Informed Services progress (December 2023)

Find out

- Using conclusions and recommendations of the Assenti Research report around autism informed services, namely:

"Enable Autistic people to communicate in their preferred way, e.g. offering digital appointments, allowing people to bring written notes, communicating in writing during the appointment.

"If appointments are running late keep the Autistic person informed.
Keep questions specific and offer examples of the type of answer they might give.
Make allowances for difficulties with executive functioning, e.g. missing appointments – offer reminders"

- NAIT mapped existing training material
- Drivers were asked what key messages should be included in all training material and shared suggestions about what training could include
- Examples of good practice recorded on a Jamboard
- Drivers compiled paper on group progress.

What needs done?

- Drivers helped NAIT complete a report from their survey
- Group decided which NHS Education Scotland level this work will focus on - agreed on 'informed'
- Group discussed the improvements needed to services
- Agreed key messages and then seven topics under a communication theme to focus on in resources.

Create

Heard from two mental health practitioners about training and what makes the most impact.

The group is creating resources, formed of:

- Short films on key themes under communication strand
- A training support resource such as an eBook or training module

The group feel that in person and autistic led training is important.

Test

The aim is to test the **resources** developed by the working group in 2024. Preparatory work included:

- NAIT suggested mental health services to contact
- Asked NES for advice on content, presentation and hosting
- Asked Autistic Doctors International for advice and input
- Outline of test ask for NHS Fife mental health team
- Share with two autistic counsellors for input on the content and use of resources. The working group used a questionnaire with baseline questions based on the experience and learning of implementing mandatory autism and learning disability training in England (the Oliver McGowan training).

Tests of change template

A test of change template, see Appendix, using an adaptation of the PDSA (Plan-Do-Study-Act) improvement methodology developed in industry and widely adopted in health settings, was developed to capture the findings and associated learning from the tests.

Use

If the tests work well, it is intended that they will be launched nationally. The group has agreed with NES that they will go on the Turas learning platform which is part of NES. This might include a Masterclass.

5. Findings and key learning points

The context and ambition

It is important to begin by remembering the context in which this work began and the ambition inherent in both its intent and design.

Towards Transformation was conceived as an interim two-year plan that followed the Keys to Life Learning Disability Strategy and the Scottish Strategy for Autism. It was created in response to the impact of the Covid pandemic on the lives of autistic people and people with learning disabilities. It embodied a desire to work differently and more collaboratively with the third sector and an ambition to work in a more direct and relational way with people with lived experience. It was launched at a time of crisis, where it was difficult to meet in person and we had to quickly adapt to meeting and working online using new

technologies, and where additional funds and resources were being made available to address a wide range of needs in Scotland's communities.

These drivers are evident in the way the plan envisages a new approach to leadership and engagement. The work being led by autistic people and people with a learning/intellectual disability is cited as a fundamental underpinning principle, and an emphasis is put on ensuring that their voice is at the centre and the heart of things, moving forward.

The leadership and engagement process was based on the belief that the 'the most effective and most sustainable change is made by the people who need and use services, in partnership with the decision makers at all levels' – collaboration also being an underpinning principle. The Scottish Government Autism and Learning Disabilities team enlisted the support of Inspiring Scotland and The Assembly who were already working alongside people with lived experience of autism and learning disabilities respectively. And a wide range of key stakeholders, including APOs and learning disability organisations, were invited to work together to identify plan and implement action to improve the way mental health services are provided to, and experienced by autistic people and people with learning disabilities.

In short, the Leadership Framework was designed as a participative co-productive process which sought to empower autistic people and people with learning disabilities to be leaders in transforming Scotland through engaging with those with the ability to make the changes needed. It depended on ensuring everyone was enabled to participate to the fullest extent, with the necessary communication supports and adjustments being made available to them.

Key learning points

The process evaluation, undertaken about a year into the Leadership Framework programme, identified a range of key achievements and challenges inherent in designing and evolving the way of working. While there was a strong consensus around the purpose and aims of the initiative, there were a wide range of views on the effectiveness of the roles, structures and processes put in place to deliver it, and these themes remained pertinent throughout.

As a consequence of this, the key learning points emerging from the programme are structured around ***Purpose***, ***Role***, ***Processes*** and ***Relationships.***

The Learning Disability, Autism and Neurodivergence Bill was developing in parallel to this work, learning was incorporated into the creation of the lived experience, stakeholders, professionals' panels and there is now an opportunity to reflect on the learning further as the Bill progresses.

Purpose

As indicated above, the process evaluation clearly identified that the commitment, determination and dedication of the Scottish Government and Inspiring Scotland team to genuine co-production has been truly appreciated by Allies, Drivers and Engineers alike.

There was a strong shared sense that the purpose of Leadership Framework was to ensure autistic people and people with learning disabilities were enabled to have their experience of accessing and receiving mental health services listened to, acknowledged and harnessed in order to shape and improve the way services are provided in the future. It was important to the autistic Drivers that their particular lived experience was bolstered by that of their peers through both primary and secondary research, and to both sets of Drivers that they were able to prioritise areas for action.

Despite this alignment around purpose, it is unclear if there was a shared sense of what success would look like and what could reasonably be achieved, by whom, with what resource, in what timescale. These tensions were a consistent underlying theme. Although the Scottish Government policy team tried hard not to over promise, and to convey the Ministerial context and budgetary position, it has been difficult for participants 'at the centre of things' not to have raised expectations.

Role

The approach relied on a wide range of people working together, bringing their diverse skills, knowledge and experience to bear. Participants were invited to take up pre-defined roles (Drivers, Allies, Engineers) which was perhaps a mixed blessing. While it helped many to understand what was expected of them and how they related to other role holders, it was confusing too. For example, some Engineers were unclear if they were there as individuals to amplify and add to Drivers issues or as organisational representatives bringing in and advocating for their interests and issues as well. The Cross Party Groups are existing fora for contributing to shaping policy and given the crossover of Driver, Ally, and Engineer involvement in these groups it may have been advantageous to include them more as the programme proceeded. The Assembly model works well; staff provide support to individuals involved in this work, and it provides ready access to the views of individual people with learning disabilities. However, an open access recruitment process for both autism and learning disability Drivers might have resulted in a more diverse and seldom heard range of voices being included.

People exercise their authority through role, and the varying language around this created differing expectations of where authority lay. For example, the Towards Transformation Plan uses a variety of terms and phrases including that the work was to be 'led by autistic people and people with learning disabilities', and that their voice would be 'at the centre of the work' and that 'the most effective and most sustainable change is made by people who need and use services, in partnership with the decision makers at all levels.'

The Leadership Framework information pack refers to putting 'their voices and experiences firmly at its heart', and later, in explaining roles/role relatedness and the governance arrangements, clearly states that 'Ministers are responsible for decision making, fully informed by the recommendations of the Engineers using the advice from the Drivers group'.

The Drivers roles evolved over time as the process moved from the experience gathering stage, through prioritising the key areas of work, to producing resources to be tested in GP surgeries and with NHS 24 and SAS. This had a direct impact on the support resources

required to enable this as well as the time necessary for successful completion, and inevitably created tensions around the speed of progress and sustainability of the initiative.

It has been challenging to involve everyone with a stake in the process, both from the outset and also at a time when they can make a genuine and meaningful contribution. Allies were more actively engaged in the early formational stages, and although they remained supportive throughout were naturally less involved as the process focussed on the creation of resources aimed at GPs and other health professionals. At various points the autistic Drivers expressed confusion around the role of Engineers and whether they should include a wider range of health professionals. In practice, the various health professionals directly involved in the testing of the resources effectively became the Engineers.

The Scottish Government policy team, supported by Inspiring Scotland and The Assembly, also adopted a more hands on and facilitative role alongside the Drivers than their usual one of 'setting the agenda', providing policy advice and advocating for resources on behalf of the process. This made it more complex when it came to delivering messages on the scaling back of resources and ambition.

Drivers were paid for their lived experience contributions in line with good practice and using the Inspiring Scotland paid participation policy (£75 for a half day and £150 for a full day in either cash or vouchers) and Assembly host Values into Action Scotland policy (£30 voucher per contribution). These differing approaches have been implemented following significant research, but the different levels give rise to potential issues around equity.

Processes

It is important to stress the complexity involved in seeking to work in such a participative equitable and relational way with such a diverse range of people. It is clear that while autistic people and people with learning disabilities experience many similar challenges accessing and using mental health services, as individuals and communities they have highly divergent needs and preferences when it comes to ways of working.

The process evaluation highlighted the need for everyone to get the information they required in an accessible format in sufficient time prior to meetings, so they had time to consider, digest and prepare for the meetings both individually and collectively. It was also clear that bringing the two groups of Drivers to work together, both online and in person, did not really work for either group. For example, the learning disability Drivers were comfortable in group settings and when they had time to process information and come to a considered view. Many of the autistic Drivers were comfortable online and made good use of the chat function to comment, question and convey their ideas in the moment.

Participatory processes always require more time and resource to ensure everybody gets what they need to fully contribute. Despite this knowledge, the pace at which work happens and decisions were made was a source of frustration for many. The Animate rapid review[10] included a systematic review[11] that concluded that 'improved social and community participation requires purposeful strategies that identify meaningful participation

[10] Good practice in participatory approaches - Animate (n 12)
[11] Frontiers in Rehabilitation Sciences (n 13)

preferences (e.g., where, when, how, and with whom) and provide support to build capacity or enable ongoing participation. Community capacity building, peer support and advocacy may also be needed to make the community more accessible, and to enable people to exercise genuine choice.'

Time was taken to establish fundamental principles, protocols and working agreements to support the collaborative process. Autistic Drivers in particular, were keen that the initiative was underpinned by a rights-based approach and a Process Monitoring Framework based on the PANEL principles[12] was adopted, alongside an autism Drivers (online meetings) Protocol', a Working Group Agreement and Meetings Planning Guidelines. These helped to build and maintain trust and mutual respect by creating a container and frame of reference against which expectations of 'how we are working together' could be reflected on, assessed and improved.

The Scottish Government policy team, supported by Inspiring Scotland and The Assembly team, consistently listened and responded to the information and communication needs expressed by the Drivers, adapting and evolving the processes throughout. Including an autistic Facilitator in the work with the autistic Drivers greatly improved mutual understanding and working practice. Similarly, the continuity and consistency of support from The Assembly programme lead and the Scottish Government Policy Officer paid dividends and, for example, enabled the learning disability Drivers to engage fruitfully with NHS 24 and SAS.

Relationships

When there is a strong shared sense of 'the why, the how and the what' participants are engaged in together, this encourages a working culture that allows for open debate and sharing of concerns. In a process as complex as this there were inevitably moments of frustration and conflict. As already highlighted, there is good evidence throughout of participants, the Drivers in particular, sharing their concerns and of them being heard and addressed by the Scottish Government policy and support teams.

7. Recommendations

'The conditions for effective collaboration are not given, they need to be created by the parties concerned.'[13] Effective collaborative processes are characterised by:

- a clear sense of shared purpose, vision, values and priorities
- clarity of roles and responsibilities, which in turn enables shared expectations and mutual accountability
- structures and processes (both governance and operational) that enable people to take up their roles in collaboration with others to meet shared priorities.

When these elements are aligned, they create the conditions for positive working relationships where people treat each other with respect, individual and collective strengths

[12] https://www.scottishhumanrights.com/projects-and-programmes/human-rights-based-approach/
[13] Sandra Schuijer, Dutch academic, specialising in action research into the dynamics of multiparty collaboration.

are recognised and built upon, and a culture that allows for open debate, sharing of concerns and resolving conflict is developed and maintained.

Accordingly, we have again structured our recommendations for future development around ***Purpose***, ***Role***, ***Processes*** and ***Relationships.***

Purpose
Having a clear shared sense of purpose, vision, values and priorities are essential to effective collaborative processes. While time was taken to articulate the ambition and intent of the Towards Transformation Plan, and to agree the underpinning principles and values, more could have been done to develop a clear shared sense of what success would look like, and what could reasonably be achieved, by whom, with what resource, in what timescale. A fuller exploration of these would help to surface differences in perspective and understanding. Even when much is uncertain it would support the progressive planning and prioritising of action and mitigate against inadvertently raising stakeholders' expectations of the scope and speed of change possible.

Role
A clear sense of roles and responsibilities, and an understanding of how the different roles relate to one another enables stakeholders to have shared expectations of one another and encourages mutual accountability. This can be facilitated by ensuring the right people with the necessary authority to take action are in place at the requisite times, and that all parties are clear about their individual and collective roles and responsibilities. The addition of an autistic facilitator worked well.

This work involved trying a different approach with Scottish Government, engaging in a different way with people with lived experience. Policy staff benefitted immensely from being involved to this extent; it helped to build relationships and trust with the Drivers and to learn more about how to engage effectively such as understanding the communication needs of the community. It also facilitated open conversations where Drivers were able to ask direct questions and receive direct feedback from officials throughout the process, albeit reflecting the time needed for an accessible participation and engagement approach. This promoted a mutually beneficial learning process. The closeness to the work meant Scottish Government staff were able to provide policy advice to participants and advocate for resources on behalf of the collaboration.

Processes
Agreed values and principles underpinning an approach provide a good foundation for establishing trust, recognising and accepting interdependencies, embracing diversity and agreeing ways of working. Establishing a way of working with a shared understanding and clarity on; the management and governance of the process, how representations are made, how decisions are made, the pace of the work, how progress is reviewed and assessed, how learning is facilitated and integrated, how disagreements are handled, will serve the collaboration well. A crucial element is being clear about the level of participation being offered to participants. Arnstein's Ladder of Participation[14] and the IAP2 Spectrum of Public

[14] https://www.citizenshandbook.org/arnsteinsladder.html

Participation[15] are useful frameworks for clarifying expectations. Similarly, being clear about the vagaries of the policy process at the outset helps contain expectations. This includes acknowledging that however compelling the 'resultant ask', it will be subject to consideration alongside a range of other priorities for scarce the Scottish Government and public resources.

Relationships

When there is good alignment between purpose, role/role relatedness and processes, working relationships flourish. Investing in creating these conditions and connections from the outset will go a long way to creating safe, healthy working relationships and a culture that is tilted towards understanding and mutuality.

[15] https://cdn.ymaws.com/www.iap2.org/resource/resmgr/pillars/spectrum_8.5x11_print.pdf

Animate

Appendix

Test of change template

Aim (overall goal for this project)			
Describe the objective for this test cycle			
What questions do you want answered for this test of change?			
Plan			
Predict what you expect to happen when the test is carried out	**Information you will gather to determine if prediction succeeds**		
List the tasks needed to set up this test of change	**Person responsible**	**When to be done**	**Where to be done**
Do	**Describe what happened when you ran the test**		
Study	**Describe the results and how they compared to the predictions**		
Act	**Describe what modifications in the plan will be made for the next cycle from what you learned**		